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ABSTRACT

This paper addresses the need to create relationships and supports that offer people with substantial disabilities the assistance they require to increase effective control of their lives ("power sharing"). The paper is based on experience and research in North American and British services to people with intellectual disabilities, autism, and cerebral palsy. The first section provides anecdotal vignettes to illustrate three different images of power sharing. The discussion that follows then focuses on four contemporary truths about disability and power sharing (such as the capability of most people with disabilities for problem solving and decision making). Power sharing is then defined in terms of its effect, its medium, the means that promote it, its absence, and the purpose it serves. Issues are itemized concerning what power sharing really implies for people with and without disabilities, such as difficulties in treating people as individuals first, regardless of the disability label. Stressed is the necessity of recognizing existing inequalities of power prior to achieving full power sharing. The relationship between the personal assistant and the individual with disabilities is considered in terms of issues of power sharing. The paper concludes with a call for new systems of service, aimed at support rather than dominance. (Contains 10 references.) (DB)

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A TUNE BEYOND US, YET OURSELVES: POWER SHARING BETWEEN PEOPLE WITH SUBSTANTIAL DISABILITIES AND THEIR ASSISTANTS

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A Tune Beyond Us, Yet Ourselves

Power Sharing Between People With Substantial Disabilities and Their Assistants

John O'Brien and Connie Lyle O'Brien*

Two fundamental and related questions challenge leaders who want to design and manage relevant human service organizations for people who need extensive and continuing personal assistance because of substantial disability. The first of these questions concerns discovering ways for people with disabilities to take a valued place in the membership and friendship networks that define community. The second question, the focus of this paper, concerns creating relationships and supports that offer people the assistance they require in ways that increase their effective control of their lives; power sharing will be the short label for this basic question.

This paper explores power sharing from the point of view of those who want to plan and offer effective assistance, many of whom will be people without disabilities. It is essential to complement this account with considerations of power issues from the point of view of people who use services (see, for example, Elwell, Platts, & Rees, 1995; Gagne, 1994; and especially Kennedy, 1996). Issues of power sharing within families that include members with disabilities, especially when mothers provide most of the assistance a person requires, deserve careful consideration, but are not the subject of this chapter (see Traustadottir, 1995). Experience and research from our perspective as nondisabled advocates for inclusive communities, undertaken mostly in North American and British services to people with intellectual disabilities, autism, and cerebral palsy, shape this paper.

* Our understanding of power sharing grows from conversations with our friends and colleagues among the members and advisers of People First of London and People First of Washington State; among the staff at Options in Community Living in Madison, WI and Jay Nolen Community Services in Los Angeles, CA, and with Ray Browning, Michael Kennedy, Fred Pinson, Cecil Rawlins, Bonnie Shoultz, Judith Snow, Steven Taylor, and Alan Tyne.

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Images of power sharing

I. Disability is no longer professional property, disabled people and their families are organizing across disability lines, and millions of dollars and thousands of careers are at stake

The photograph shows a girl of five holding a sign almost as big as she is in one hand and her mother's skirt in the other. Next to her are two heavyset men in their mid-thirties. All three are listening as legislators respond to the demands their group has presented. Ray sits with one hand against his head in a signature gesture of concentration. Larry stands with one hand on the back of Ray's wheelchair, which he has pushed along the route of march to the steps of the Georgia State Capitol. The little girl's features identify her Down Syndrome to anyone familiar with its typical characteristics. Her sign, neatly lettered by her mom, reads, "'Leah' is the only label I require!"

Ray has lived for the past 14 years in a nursing home, where the professionally affixed labels of severe cerebral palsy and moderate mental retardation have earned him the privilege of federally financed "total nursing care". For about two years, with the support of a growing number of allies, he has worked hard "to get out and get into my own place so I can be in charge of my own life and get a job." This is difficult in Georgia because hundreds of millions of government dollars pay institution and group home operators and only a few hundred thousand dollars are available statewide to fund the kind of personal assistance system Ray and his circle of support have designed. He would not miss this rally, which he helped to plan as a member of SAN: The Self-Advocacy Network.

Larry is president of the Mental Health Consumers Coalition. He has worked hard to organize more than 1,000 people who regularly require significant supports from public psychiatric services. He wants to make sure that the Legislature doesn't buckle under pressure from medical-bureaucratic interests and roll back administrative changes passed in the last session. His whole life is committed to creating a system that recognizes disabled people's right to control their own lives. And today he is Ray's personal assistant.

Leah and her mother have joined the lobby because Leah's mom opposes the funding bias that handsomely rewards schools for segregating children with disabilities and fiscally punishes schools that work for inclusion.

II. Staff must deepen their relationships by learning from the people they support if they and their agencies are to offer relevant assistance.

Tackling her assignment to write a story about her work to read at the next all-staff meeting, Julie reflected on an incident that might otherwise have slipped by as one busy day followed the next in her work as a supported living coordinator. She wrote (from O'Brien & O'Brien, 1992, pp. 63-64):

> "Christa, tell me about camp...You were so excited to go this year. How was it?"
>
> "OK...But you're not going to like it."
>
> Christa's body tightened and flexed in her wheelchair... a posture I have come to recognize as expressing anger or excitement... "I'm supposed to be independent, but I left my camera at camp." Nearly breaking into tears, she explained that she had reminded her camp counselor to pack it but that it had obviously not been put in her suitcase.
>
> Christa was angry at herself for failing to live up to the high standards she holds for herself, and afraid that I would, therefore, be disappointed in her. Why wasn't Christa telling me about singing around the campfire, swimming, sunning, seeing old friends and making new ones? Why did the loss of a cheap camera overshadow everything else that had happened at camp, and why was she afraid of my reaction?
>
> Somewhere along the line, Christa had interpreted messages about autonomy and independence to mean simply that she has to be perfect, like us service providers. To be in charge of her own life, she thinks that she can't afford to make a mistake, to look stupid, to laugh at herself, to enjoy life, to be human. Seemingly unimportant, everyday events take on monumental significance in Christa's struggle to live up to that perfect image that others have helped to create for her, in spite of the fact that she often has very little control over what happens.
>
> After this one brief conversation I felt like I knew Christa better. I also realized that my challenge is to let Christa know me better; to know my fears, my weaknesses, my mistakes. To know that mine is not a perfect image to aspire to.

III. Power sharing means opening new opportunities and creating new relationships that do not respect established boundaries in communities or in service agencies.

Chris and Dan and Adrian wave in response to the Customer Service Supervisor's greeting and push through the big double doors that separate the sales floor from the stock room of the newest Marshall's Department Store, built to replace a store destroyed in the Los Angeles earthquake. Chris and Dan clock in and go to the loading area to wait for a moment while Adrian checks the assignment sheet and pushes the day's work down a long line of steel rollers. Today it's a large container of beach shoes to inspect, tag, security code, and

place in display boxes. Chris and Dan divide the tasks and set about their work.

Adrian worked as the stock room supervisor at another store in the chain until he took a job providing live-in support to Chris, who had recently moved from a group home into his own place, a small house not far from the university Adrian plans to attend. It is hard for people to understand Chris's communication, and, when he lived with five other people with autism, behavioral outbursts were Chris's most reliable way to claim the space he needed or to make it clear that he was not interested in an activity.

As Adrian got to know Chris it became clear to him that Chris hated the day program he attended. He was active and happy as he settled into his new home, where no one disturbs the newspaper until Chris has finished with it, where he can use his comprehensive knowledge of the TV guide to select the specific shows that spark his interest without competition from staff who want to watch something else. But getting ready and leaving for the activity center was the hardest time of the day. Chris's circle of support was sure that he would prefer a job to the activity center; the only possible downside of leaving the day program would be missing a chance to be with his friend Dan. But the supported employment team just couldn't seem to find him a job.

Adrian decided that Chris would wait forever while the supported employment team got itself together. He took Chris and Dan to meet the manager of the new Marshalls nearby –someone Adrian had worked with previously. At Chris's and Dan's next circle meetings he made a proposal: Chris and Dan would work together 10 to 20 hours a week, with Adrian as their support worker. Each circle had a number of problems to solve before they accepted the proposal, including dealing with protests from day service and supported employment staff about Adrian's invasion of their turf.

No one thinks Chris or Dan has more than scratched the surface of their work lives.

The question of power sharing can't be avoided

Some might argue that the very idea of power sharing is dangerously naïve, if it is not disingenuous. There are at least two different foundations for this argument. On one view, paternalism, professionalism, and prejudice deprive people with disabilities of their rights; it is not power sharing that matters but power, full stop. Disabled people must organize and struggle to take the power that is theirs by right. Those with power will not give it up, those who are oppressed must confront them and seize it. It is pretty to think of power sharing, but it amounts to little more than a New Age mask for the denial of real rights.

On another view, speaking of power sharing, at least as far as people with severe intellectual disabilities is concerned, is a euphemism, amounting to a denial of the reality of disability. Once again the issue is power, period. The strong and able must protect, guide, and oversee the weak and incompetent. If trendiness leads protectors to shirk their duty in the name of choice, vulnerable people will suffer the conse-

quences of abandonment. It is pretty to think of power sharing, but it amounts to little more than a politically correct rationalization for ignoring the obvious incompetence of people with intellectual disabilities.

These apparently divergent arguments mark the boundaries for this discussion of power sharing, a discussion which only has meaning among people who recognize four contemporary truths about disability.

One, people with cognitive and communication disabilities are far more capable of problem solving and decision making than most people have thought. Given the same kind of supports as anyone else –accessible information, ideas about alternatives and resources, ways to think about problems and decisions, others who are willing to listen and question and test assumptions and conclusions– most people with intellectual disabilities have a very strong interest in taking greater charge of their own lives. Like people without disabilities, people with intellectual disabilities can get mixed up by emotional conflicts or competing interests or wishful thinking but these human weaknesses don't justify ignoring their agency. There are probably a few people whose impairments make even their ability to express preferences uncertain, but wisdom lies with those who remember the historical lesson that the most likely errors to make about a person with a disability are errors of underestimating ability and denying common humanity.

Two, people with significant disabilities cannot take even the most basic human and civil rights for granted. Their exclusion from ordinary settings and relationships, and their presumed need for professional control, remain unquestioned in all too many settings and still shape most social policy (see Trent, 1994 for a history of the ways that service providers have responded to changing social forces by entwining care and control for their professional advantage). Even people with disabilities who have good supports and opportunities can all too easily slip into isolation, neglect, and abuse. Sustained, strategic, committed civic action for justice, by organized groups of people with disabilities and their allies, is a necessary condition for dealing with the consequences of generations of prejudice. Those who speak of power sharing but make no contribution to the struggle for disabled people's rights narrow their understanding of power by masking and denying social inequality.

Three, even the deepest regard for rights does not erase vulnerability and the quandaries of protection. Short of utopia, those who are weaker because they require assistance will look like easy prey to exploitative and abusive people. Even given the best technical help, people with intellectual disabilities must trust others to help them interpret complex situations, and people with significant intellectual disabilities must trust others to make at least some important decisions for them. Despite good support, some people who rely on others for assistance will at times act in self defeating or even self destructive ways or will come into conflict with the law. Those who speak of power sharing but refuse to consider the obligations and dilemmas of protection will leave many people with substantial disabilities out of their

revolution.

Four, there is a real imbalance of power between people with disabilities and their assistants. How this asymmetry is understood and managed determines the quality of everyday assistance, which strongly influences how people with disabilities contribute to the struggle for human rights, and how they experience necessary protections. The advantages of being in charge of another person can lead nondisabled people to accept power over the other without question, as an inevitable consequence of disability. The desire to promote people's rights can lead non-disabled people to ignore and deny real inequalities. Neither unquestioning acceptance of the proposition that assistants take charge because they know better nor an uncritical belief that respecting another person's dignity wipes out the consequences of real inequalities will do. Those who speak of rights or protection without engaging the fuzzier, more connected questions of sharing power will be left without the human context for realizing either goal.

What is power sharing?

Each of these approaches to definition captures a facet of power sharing between people with disabilities and their assistants.

Power sharing can be defined by its effect – people with intellectual disabilities can participate with satisfaction in ordinary activities that reflect and strengthen their individual capacities and gifts because of the active and imaginative collaboration of their assistants.

Power sharing can be defined by its medium – conscious relationships in which people commit themselves to overcoming the barriers that stand in the way of people with disabilities realizing their dreams, especially when these barriers are erected by prejudice and discrimination. (Defining power sharing by reference to people's dreams calls for further discussion, which will be found below.)

Power sharing can be defined by the means that promote it – assistants make themselves physically and emotionally available to understand, accommodate, and promote the explorations, participation and contribution of people who would otherwise be excluded or marginalized because of the social and physical effects of disability.

Power sharing can be defined by its absence – people with disabilities are not even ignored, others presume that they have nothing to say and no way to say it; their contributions are not even rejected, others presume they have nothing to contribute; they are simply the raw materials for low status daily work and higher status professional control.

Power sharing can be defined by the purpose it serves – community life will be richer, deeper, and stronger when people who have been devalued and excluded are welcomed and included and expected and assisted to contribute to common life. Community life is narrowed, weakened, and wounded when people are exiled, isolated, and dominated because of disability. People with significant disabilities can be community builders, but only if some of the people close to them join, and amplify, their desire to reveal and realize their dreams.

Shared inquiry into power

Power sharing happens daily between people and their assistants. The consciousness necessary to extend and deepen power sharing grows when those who use services and those who plan and provide them can join from time to time to create a forum that allows exploration of the effects of agency culture, policy, and social contexts on their relationships. Such a forum contributes to power sharing by its constitution: all participants have a voice whether they are disabled or not, whether they use services or provide them, and all participants direct their attention to the question of what possibilities for collaboration they want to realize and what constraints they will work to overcome.

In one such forum in the United Kingdom, Alice Etherington (1994), a People First leader, summarized the terms for serious debate around power sharing. She addressed these questions to non-disabled participants.

> Before you say you are on our side, ask yourself...
>
> ...do you see and treat us as people first, or do you try to wrap us in your labels?
>
> ...do you listen with respect to how we want to live, or do you think you always know best?
>
> ...do you recognize that we have the same kinds of rights and desires as you do –for our own home, and a decent job, and the chance to learn, and friends and lovers– or do you see us as second class people?
>
> ...do you answer fully and honestly or do you hold back information?
>
> ...do you say things in plain words or do you try to put us down with jargon?
>
> ...do you do what you say or do you make empty promises and run away as soon as things get difficult?
>
> ...do you expect to change your jobs and your programs and your rules or do you think we should do all the changing?
>
> ...are you ready to give us control of the money or does your job come first?

Power sharing does not mean simply switching the command position and mindlessly doing whatever people with disabilities say; that would be power switching not power sharing. There is much to debate with Alice Etherington and other leaders among people with disabilities: What effects would handing the service system's money over to people with disabilities produce? When is it legitimate to take control of another person in order to protect that person or others? When is it helpful to describe people's impairments with professional jargon? How much is it reasonable to expect workers to change themselves to accommodate the preferences and choices of the people they assist?

What is indisputable are the terms in which she frames power sharing. Policy makers and staff who are serious will find ways to listen with respect and respond fully and honestly as people. They will take responsibility for dealing with the effects of prejudice on what they hear

and decide to do. They will take initiative in sharing information and surrender the tactics of secrecy and using jargon for control. They will consider the effects of poverty and lack of control over funds on people's lives and look for ways to respond constructively. They will stick with people when the going gets hard.

What is also clear is that people with disabilities must be full participants in exploring the effects of power on their lives. There are complementary arts to creating an effective forum, arts that are hard to practice and easy to slip away from, because cultural patterns of inequality easily dominate efforts to displace them, even temporarily (Martin-Baro´, 1994). To practice these arts, non-disabled people make room for the perspective of those they have learned to view from the outside, as objects of classification and control. They practice critical examination of the assumptions that have shaped an unequal situation in which they have the advantage. They learn to face their fears of ambiguity and change without the ready defenses of detached professionalism. To practice these arts, people with disabilities find ways to publicly express thoughts and aspirations that have been held close for fear of ridicule or retribution. They search for new information, new ways to understand, and new possibilities for contribution. They learn to move through withdrawal, blaming, and angry demands toward opportunities for collaboration. To practice these arts, everyone grapples with finding effective ways to include more people whose ability to understand and communicate is in question. Everybody brings their wisdom and creativity to bear on shaping practical ways to bring people together to resist and change policies and cultural patterns that blight people's opportunities for contribution.

Power sharing grows with the recognition of inequality

Sharing power grows from an understanding of who has got what kinds of power.

Like anyone else, people with disabilities have power commensurate with their position, their possessions, their skills and abilities, their interests, and their gifts. More than most others, people with substantial disabilities are likely to be isolated from positions of power, impoverished, left with underdeveloped skills due to low expectations, denied opportunities to pursue their interests, and ignored as unable to bring important gifts to a community's life. Enumerating these obvious limits suggests an agenda for shared action to promote justice by increasing the power of people with disabilities: open valued roles to people who have been relegated to the margin; increase personal income and economic security by decreasing public expenditure on services that congregate and control and re-investing in cash transfers, vouchers, or subsidies; heighten expectations and offer intense and relevant opportunities for education; reduce barriers to people developing their interests; develop the hospitality of associations that will be strengthened by the gifts of excluded people.

For many people with substantial disabilities who rely on services, shared action depends on staff collaboration. Here, puzzlingly, there often seems to be a power shortage. Commonly, service staff, and

even agency or service system managers, present themselves as nearly powerless in the face of heartless managers, stingy politicians, ignorant and unsympathetic citizens, unmotivated and unappreciative clients, punitive regulators, greedy tort lawyers, and domineering parents. This abdication has at least two bad consequences: first, it makes room in the shadows for the misuse of the real power staff and managers have in the lives of the people they assist, and second, it directs attention away from the possibilities for increasing accomplishment by sharing power.

The first step in dealing with the power shortage among staff and managers is to encourage them to analyze the power they exercise in the lives of the people with disabilities who rely on them. There are at least three sources for the imbalance of power that favors staff people. First, because people with significant disabilities require daily, sometime hourly, personal assistance with basic activities, and often need cognitive facilitation to understand information and make decisions, their assistants have power over them. By the way they do necessary tasks, they can encourage people's preferences or trap them in inflexible routine; they can give people reason to feel secure or anxious about their worth or even their physical safety; they can amplify people's voices by active listening or they can ignore and extinguish them. Second, no matter how poorly they are paid or how low their status, virtually all staff have more control of their everyday lives than most of the people they support, and they are accorded greater credibility in their accounts of situations. Third, staff have a ready option to exit –moving on or up to another job if their work with a person becomes unsatisfactory– while very few people with disabilities can initiate changes of assistants or service providing agencies, despite the increasingly common practice of euphemistically labeling them consumers. Real and enduring power imbalances can't be legislated or wished away, though laws can help set limits on the way assistants act and policy could offer people more disposable income and choice among real alternatives to unsatisfactory assistants or service agencies.

People with significant disabilities depend on the ability and willingness of their assistants to work ethically, imaginatively and unobtrusively. This is so even when people are as assertive as they can be; an activist whose assistant shows up late to help her out of bed will miss the demonstration she organized. This is so even when people make the best possible use of assistive technology; if no one plugs in the battery charger, a communication device becomes a paperweight. This is so even when extreme cognitive limitations make a person reliant on others for even routine decision making: assistants who attend carefully and respectfully to a person's moment by moment expressions of preference and identity enrich and deepen the stream of information available to substitute decision makers. This is so even when a person's dangerous actions raise the threat of sanctions or imposed controls; assistants who invest the time and attention to get to know and respect a person have far better chances of preventing dangerous situations from developing, negotiating better resolutions to conflicts,

and involving the person in constructive problem solving to deal with troublesome consequences than those who can only resort to trying to outwit or overpower the person.

A deeper understanding of the power assistants do exercise creates the possibility that they will search for ways to collaborate with the people they assist to change the conditions of inequality that constrain and distort their relationship.

From inquiry to practice

Michael Kennedy (1996), an activist for disability rights who grew up in institutions and uses personal assistance services, identifies power sharing between people with disabilities and their assistants as a process of shared learning. This process cannot be codified in definite policies because it has to respond to changing circumstances around the person and to growth in the person's understanding and ability. He notes that he is not striving to be independent from his assistants (available technology makes that outcome unlikely) but for teamwork with them. While he wants the responsibility for the final decision when there are disagreements, he does not dictate to his assistants because they have valuable ideas to offer him. Trust and joint responsibility for learning are the keys to teamwork.

Kennedy's experience as the employer of his assistants –still an unusual arrangement– highlights reciprocal responsibilities rather than unilateral control. People with disabilities educate themselves about what assistance they need and how best to let others know how to assist; they work on learning from experience what is desirable and what is not. Assistants do not hold a person's need for assistance over their heads; they educate themselves about ways to help, make suggestions, actively involve themselves in identifying and solving problems, and respect the person's responsibility for making the final call when there are differences of opinion over the best way to do something. People with disabilities consider advice, suggestions, and personal feedback from others they trust and strive for open and honest relationships. Assistants offer suggestions and information based on their efforts to learn to support the person better. People with disabilities take account of the assistants' dignity and feelings when giving instructions or correcting unsatisfactory performance. Assistants avoid imposing their preferences unless the assistant feels that the person is asking the assistant to do something the assistant believes would be wrong. Both people with disabilities and assistants have the opportunity and the obligation to grow as people worthy of each other's trust.

Remembering his institutional experience, where he was frequently and brutally punished by staff who resented his speaking out and reporting neglect and abuse of other inmates, he says, "Even with all the abuse, I always kept in mind that there had to be someone out there who would have the heart and compassion to listen. I didn't find very many, but there were three key people who did." (p. 41). These three people were instrumental in his continuing to speak up for what he knew was right and in his escape from the institution.

How much does power sharing depend on a persons ability to com-

municate? Those exploring the frontiers of power sharing are searching for better ways to understand and accommodate people's preferences and personalities. This often involves constructing a detailed account of what those who know and care about a person believe makes an important difference in the quality of their days. Smull (1995) describes the initial results of such a process for Rhonda, a woman whose primary medium of communication is body movement within a restricted range. Among other things, those who know and care about her believe that she prefers sitting in sunlight; she enjoys the warmth and sound and smell of the clothes dryer when it is turned on; and she signals her readiness to get up in the morning by turning on her stomach. For Rhonda, power sharing begins when her assistants take direction from these statements about her preferences and watch carefully for opportunities to correct, refine, or extend them. There is a danger that those who care about her are just making things up. This danger must be tested by asking, "If we are wrong about this, what will be the consequences to Rhonda?" It should also be weighed against the costs of not providing Rhonda's assistants with the best available guesses about her preferences.

In dreams begin shared responsibilities

If power sharing is a process of mutual learning based on trust, it cannot be compelled or controlled by bureaucratic procedures. Because it runs counter to established beliefs and common practices, those who wish to practice power sharing need to find a deep foundation for their relationship. One way to dig this foundation is for both the person with a disability and the person's assistants to seek to discover and serve the person's gifts. One way to understand this search is to describe it as a search for a person's dream.

Out of her experience of liberation from institutionalization, Judith Snow (1994) articulates the possibility of a person's dream giving direction and structure to the life they share with others. In this sense, dreams are taken to be expressions of identity that give rise to images of what a person is called to contribute to his or her community. These images of identity and vocation offer indications of the choices that are right for a person. These images link the dreamer to others who share the dreamer's purpose, and to a community that will grow richer through the dreamer's gifts. As the dreamer lives the dream, new images emerge. Person-centered planning processes create occasions for clarifying current expressions of a person's dream and defining the kinds of opportunities, supports, and activity that will support further expression of the person's individuality.

Our common life will be stronger if each of us recognize and cultivate the talents of inviting, listening carefully for, and joining in the realization of one another's dreams. Since dreams arise beneath words, people with no, or very limited, verbal ability can be powerful teachers on the possibilities and dangers of seeking to discover and join in supporting another person's dreams.

Dreams pose fundamental questions to the dreamer, questions that friends and allies have an obligation to help the dreamer explore:

- What matters most to me; what gifts am I responsible to develop and offer?
- Where does my dream make sense; what social settings provide opportunities to offer my gifts?
- With whom does my dream make sense; who can help me strengthen my gifts and create opportunities for their expression?
- What resources are essential to the pursuit of my dream and how can I gain control of them?

The answers to these questions provide the foundation for collaboration by identifying what is most important for the person.

Three other common understandings of dreams compete with this one. Many people dismiss dreams as mere reverie, idle fantasies to escape boredom. Some people view dreams as symptoms, expressing psychic conflicts rather than individual and communal possibilities. Others degrade dreams to consumerist material desires; things in an image –like a car or a house– get treated as ends in themselves which are either "realistic" or "unrealistic" to wish for, rather than as indicators of individual possibilities for meaningful contribution. At a particular moment in life, reverie, symptom, or compulsion to consume might be no more than that, but each might point toward a person's identity through the art of imaginative listening. "Do any of these idle fantasies feel like they point to something important?" "What gift is tangled up in this symptom?" "Where do you go in your new car and what do you do when you get there?"

Forming a new kind of organization

Power sharing subverts the logic of existing service organizations which are based on the oversight and control of people with disabilities. Whether this unilateral control is justified on therapeutic grounds or asserted as a necessary form of social control or presented as a key to the happiness of diminished people, its form allows no significant power sharing. Evolving new service forms, based on shared power between people and their assistants, challenges and threatens everyone involved in the design and management of services.

Handling the question of how to design service organizations so that their staff share power with people who have obvious and significant differences in movement, communication, learning, and self control means holding onto something hot enough to melt many of the structures and alliances that make managers' jobs tolerable. Plenty of emotion is bound up in organizational routines and rituals that allow staff and agency sponsors to overlook ignorance of a person's identity, uncertainties about what a person might prefer, conflicts over the prudence of a person's judgment, life directions that call on staff to learn to do new things in new ways, and the suffering imposed by unjust and devaluing social and cultural processes.

No wonder that for years this heat was quenched in safe controversies: When can clients attend the meetings that plan their individual program? If they attend, how will we deal with them if they make unrealistic demands? Which residents will be allowed to set their own bedtimes? How will we motivate consumers to take more responsibility

for following their prescribed regimen of treatments? What issues can the self-advocacy committee be allowed to tackle? Will we have a client on the management committee? Though these questions can generate much controversy, they remain safe questions in that none of their answers challenge the structures, ideas, and relationships that form the service.

Lately, some managers have found a new safety zone by diverting the fundamental question of power sharing into issues of what techniques staff will use on people with disabilities within the existing structures. They are pleased to allow professional staff to adopt training and counseling methods aimed at bringing clients systematically toward the goals of "empowerment" or "self-advocacy". They are proud to share their new vision of clients as "customers" and the many variations of "total quality management" techniques they have adopted. They are glad to say that they are "shifting their paradigm"

In the midst of all this comfortable trendiness, a growing number of people have found the courage to hold onto the question of power sharing, and with exciting results. More and more people with substantial disabilities have found their voice and called managers and staff into new kinds of relationships, relationships which have encouraged them to leave behind restricting service forms. The heat of power sharing has melted controlling group residences and shaped new forms of supported living and lifesharing. It has melted mindless or feudal occupational routines and shaped new forms of supported employment and active concern for career and vocation.

These new containers for service, aimed at support rather than dominance, are in their formative stages. How exactly they will develop, and what more will be required remains to be seen. But the test of their effectiveness, and the means of steering their development, is clear: because of the way assistance is provided, do the people served, and their assistants, become better and better able to collaborate on actions that contribute to a stronger, richer, more diverse community?

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